Routine integration of palliative care: what will it take?

Palliative care is an essential component of quality care in advanced illness

Palliative care has substantial benefits for patients with advanced disease, including improved symptom relief, quality of life, and communication around health care goals. These benefits extend to the patient’s family, improving caregiver quality of life and bereavement outcomes. Palliative care is also associated with cost savings with reduced hospitalisations and emergency department presentations, and greater likelihood of death at home.

Despite these proven benefits, there is variability in access to palliative care and many patients are not referred in a timely manner. Although 62% of patients with metastatic lung cancer in Victoria are engaged with palliative care services by the time of death, most are referred in the final hospital admission, during which they die. These patterns are reflected nationally and internationally, with a median survival following admission to palliative care programs of 22–54 days, suggesting late referral.

The timing of referral to palliative care or adoption of a palliative approach appears to be important in achieving benefits. Late referral leaves little time to establish confidence in community-based care, or to undertake complex communication tasks, such as exploring values and establishing goals for care. Barriers to timely engagement with palliative care include limitations in workforce and service models, availability of services, failure to recognise poor prognosis or patient needs, and fear of destroying hope or upsetting patients. Indeed, when referral to palliative care is raised, some patients are distressed but they also report interest in its components, namely access to symptom control, psychological and family support, and assistance with decision making. Bereaved carers report a wish for earlier engagement with palliative care in their relative’s illness.

So how may we improve routine integration of palliative care in advanced illness? A whole-of-system approach has been advocated, involving quality-improvement strategies that identify and respond to specific gaps in care, coupled with measures of achievement and accountability.

Yet, even in systems without barriers to palliative care, there remain two clinical tasks that appear critical to its successful integration: recognition of the possibility (and need) for palliative care, and sensitive communication.

A number of prompts have been proposed to ensure the task of recognition occurs. These include disease specific prognostic tools, measures of need both symptomatic and psychosocial, and clinical prompts such as “would I be surprised if this patient died in the next 6 months?”. An alternative approach based on service use, such as increasing frequency of admissions, or the development of a nominated disease complication such as metastatic disease, may offer an administrative prompt that occurs routinely and requires a response, rather than initiation, by the physician.

Once recognised, there remains the task of communicating with the patient and family around issues of worsening disease, disability and death. Yet, our society determinedly avoids discourse around dying, focusing instead on “staying positive” and “fighting hard”. The media reinforces this language and focus, offering few stories of those whose illness progresses. This silence is also present in the clinic, and so instead we frequently find it easier to offer a further round of treatment rather than discuss the implications of failure of the last. By failing to engage patients and their families in such discussion until death is imminent, we limit opportunities of patients to realise choices in the final phase of life.

Given these significant barriers, how do we promote palliative care to patients and their families? Perhaps patients themselves offer the solution. When asked, patients are clear about what is important at the end of life, and much of this revolves around successful communication and subsequent planning. They want a holistic approach to their care that embraces their hopes for living even as they die. They want to be free of pain and other symptoms, so that they may realise goals in the personal realm. Palliative care represents a philosophy of care that facilitates these goals and should be explained to patients in these terms, as a set of practices oriented towards achieving their nominated wishes.

Successful integration of palliative care in the future will therefore require not just access to quality services, but also recognition of the final phase of life and a willingness by physicians to have this difficult conversation with patients. This conversation should include a careful exploration of the patient’s understanding of the disease, a discussion of possible outcomes, establishing the goals of care, and then, as appropriate, an explanation of tasks of palliative care and how these might be relevant to these goals. Without engagement with this communication, any future possibility for integrated quality care based on patients’ preferences for the end of life will likely be lost.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed.

References are available online at www.mja.com.au.


